

Low level of knowledge regarding diagnosis and treatment among inpatients with schizophrenia in Shanghai

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Objective: The study was designed to measure the level of knowledge of the diagnosis of illness and its treatment among patients with schizophrenia in China, and to examine the association between the capacity to provide informed consent and participation in treatment.

Participants and methods: A cross-sectional study was conducted at three clinical inpatient sites in Shanghai, China, during 2015. Patients' knowledge of the illness, as well as the knowledge of the patients' families and psychiatrists, was determined. Logistic regression was used to determine the factors associated with patients' knowledge of schizophrenia.

Results: Out of 109 enrolled schizophrenic inpatients (mean age 42.46±1.29 years), 60.6% were aware of their diagnosis and 67.0% knew details of their treatment plan. The group with unimpaired capacity for giving informed consent had a greater knowledge of their diagnosis ($\chi^2=5.002$, $p=0.038$) and of their treatment plan ($\chi^2=11.196$, $p<0.01$) in comparison with patients who were regarded to be impaired. Using logistic regression analysis, it was found that patients' capacity to give informed consent to treatment was associated with the level of knowledge surrounding the diagnosis (odds ratio =3.230, $p<0.05$) and the level of knowledge of treatment (odds ratio =4.962, $p<0.01$).

Conclusion: The level of knowledge reported by inpatients with schizophrenia was low with respect to the diagnosis of schizophrenia and of the treatment associated with this illness. An association between patients' capacities for giving informed consent and knowledge of their illness was confirmed in the present study. The results suggest that, in clinical practice, the informed consent process should be strengthened to protect the interests of patients with schizophrenia.

Keywords: ethics, informed consent, schizophrenia, illness knowledge

Introduction

Schizophrenia is one of the most common and severe mental disorders, affecting approximately 60 million individuals globally.¹ The World Health Organization estimates that the care of schizophrenic patients consumes 1.6%–2.6% of health care expenditure in the West.² Because schizophrenia is often a chronic condition, in many cases, long-term treatment is necessary. As a basic ethical duty, the sharing of information concerning diagnoses of mental illnesses and outcomes should be part of any treatment plan from the earliest stages of any intervention.³ However, studies conducted in Western and Asian countries indicate that low levels of knowledge about diagnoses exist among schizophrenic patients.^{4–6} Educational initiatives relating to the treatment of schizophrenia-related disorders are often directed at family members and physicians, as patients with schizophrenia are viewed as being unable to make rational decisions.^{7,8}

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In a recent Chinese study, it was found that in most cases it is guardians who provide the necessary informed consent for treatment. This practice could be considered to be a violation of patients' rights.⁹ In other recent studies, it has also been reported that the stigma associated with schizophrenia has had a negative impact on the disclosure process.¹⁰ Patients with schizophrenia, by virtue of their illness, are often not involved in their own treatment and recovery process.

With increasing global awareness of mental illness, which has spread to China, more professionals realize that it is important to invite schizophrenic patients to participate in treatment choice and that they should agree to a chosen treatment plan. Zhou demonstrated that obtaining patient agreement to a treatment would be one way of improving treatment adherence in patients;¹¹ the involvement of patients in their own treatment, he argues, would lead to healthier behavior and improved treatment outcomes. In some earlier studies, attitudes of patients and the general public to an increased understanding and awareness of mental illness in China have been discussed,^{12,13} but there are few studies reported in the literature to indicate the knowledge of the schizophrenics' personal illness and their participation in treatment choices.

Our hypothesis was that the level of knowledge with respect to illness diagnosis and treatment, and patient involvement in treatment choices in schizophrenics is in the mid-range. Patients with schizophrenia could be impaired with respect to their capacity to give informed consent, which would be the most important reason for psychiatrists not disclosing information about their illness to them. So, it was assumed that a greater capacity to provide informed consent would be associated with a greater knowledge of the illness and higher participation in treatment choices.

Participants and methods

Participants

Patients were sampled from one tertiary hospital (Shanghai Mental Health Center) and two secondary hospitals (Shanghai Changning District Mental Health Center and Shanghai Hongkou District Mental Health Center). Inpatients at three sites with an ICD-10 diagnosis of schizophrenia, aged 18–65 years, with 7 years+ in formal education, were invited to join the study. The participants had to be able to communicate adequately and to understand the purpose of the study. The exclusion criteria included comorbidity with other mental disorders, diagnosis of other neurologic disorders, and having previously received electroconvulsive therapy treatment.

Between July and November 2015, a total of 109 inpatients participated in the study, among them 59 were drawn from the tertiary hospital and 50 from the secondary hospitals. Family members who accompanied participants to clinics and attended consultations with the psychiatrists responsible for the patients' treatment were also invited to respond to a six-question, self-reported questionnaire, which replicated the questions asked of the patients. All patients and their family members provided written informed consent. The study protocol was approved by the Shanghai Mental Health Center Institutional Review Board (No 2015-21).

Measures

Diagnoses were confirmed using chart reports recorded by psychiatrists according to ICD-10.¹⁴ Demographic and clinical information was collected from the chart information. Illness severity was evaluated using the Clinical Global Impressions-Severity scale (CGI-S),¹⁵ which was a three-item, observer-rated, 7-point subscale, using a range of responses from 1 (normal) through to 7 (among the most severely ill patients).

The Chinese version of the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) was used to assess the patients' capacity to give informed consent for treatment. This was a semistructured interview in simplified Chinese, which Yi et al¹⁶ have previously shown to be a reliable and valid measure of the capacity of diagnosed schizophrenics to give consent. In total, there were six raters involved in data collection, all of them were attending psychiatrists. Standardized training in administering MacCAT-T was provided to all the raters. The training consisted of 1-day theoretical training and scoring video; the raters had good interrater reliability (intraclass correlation coefficient [ICC] = 0.97, $p < 0.01$) assessed the capacity of patients to give informed consent in four parts: understanding, appreciation, reasoning, and expression. The results of MacCAT-T were dichotomized in two categories: "impaired" or "unimpaired." The cutoff defined for the "impaired" was in agreement with the study of Vollmann et al:¹⁷ for understanding, ≤ 4 ; for reasoning, ≤ 3 ; for appreciation of disorder, 0, and for appreciation of treatment benefit, 0. Patients were considered to be "impaired" if they were impaired in at least any two of the standards.¹⁷

A six-question, self-reported form was developed for patients to collect the patients' degree of knowledge about their personal illness diagnosis and treatment plan, their degree of participation in treatment options, and attitudes toward the rights of patients to express consent (Table 1). Questions 1–3 and 5–6 required Yes/No answers only.

Table 1 Questionnaire

Question
Q1: Do you know the name of your illness diagnosis?
Q2: Do you know what treatment you are getting?
Q3: Have you participated in your treatment plan decisions?
Q4: Do you think you can make clear decisions during your illness?
Q5: Do you think you should be told about your illness diagnosis and treatment plan?
Q6: Do you think you can refuse treatment?

Question 4 required a response of either “less than half the time” or “more than half the time.” A separate questionnaire for family members consisted of six questions similar to the questionnaire for patients, addressing the family members’ degree of knowledge about the patients’ illness diagnosis and treatment plan, their degree of participation in treatment options, and attitudes toward the rights of patients to express consent.

The knowledge of illness diagnosis and treatment plan used in this study was measured by the self-reported questionnaire (Table 1) among the inpatients with schizophrenia. The respondents were asked whether they knew about the illness name and symptoms with respect to the knowledge of illness diagnosis. The knowledge of treatment plan referred to the name of treatment they were getting, the effect and side effect of the treatment, and duration of the treatment.

Statistical analysis

Data were entered into EpiData 3.1 (EpiData Association, Odense, Denmark) and analyzed using SPSS 19.0 (Statistical Package for the Social Sciences Co., Chicago, IL, USA). The frequencies and corresponding percentages for dichotomous variables or medians and interquartile ranges for continuous variables were calculated. Descriptive statistics were performed in order to examine the degree of knowledge of illness and treatment across patients with differing demographics and characteristics. χ^2 tests were used to investigate group differences for categorical data, and analysis of variance was used for continuous data. The concordance of two groups was evaluated by Cohen’s κ coefficient. Logistic regression analysis was performed to assess the factors independently associated with illness knowledge and participation in treatment. The significance level was set at 0.05 (two-tailed).

Results

Demographic and clinical characteristics

Schizophrenic inpatients (109) with a mean age of 42.46 ± 1.29 years and a mean time spent in formal education of 12.67 ± 0.26 years participated in the study. Patient demographics are

displayed in Table 2. Patients who resided in urban areas were more likely to have more knowledge of their diagnosis ($\chi^2=5.491$, $p=0.026$) and treatment plan ($\chi^2=4.405$, $p=0.043$). Patients who had achieved a higher educational level ($\chi^2=9.142$, $p=0.01$) and had demonstrated better social functioning in the previous year ($\chi^2=9.811$, $p=0.02$) were more likely to know more about their treatment.

Knowledge of a patient’s diagnosis and treatment

The rate of patients’ knowledge of diagnosis was 60.6% and about treatment was 67.0%, and the rate of participation in treatment choices was 25.7%. Compared with the patient, family members had a better knowledge of patients’ diagnoses (90.8% vs 60.6%, $p<0.01$) and treatment (83.5% vs 67.0%, $p<0.01$), and were more closely involved in treatment options (61.5% vs 25.7%, $p<0.01$) (Table 3).

Over two-thirds of psychiatrists thought the patients knew about their diagnosis, which was consistent with patients’ own reporting ($\kappa=0.462$, $p<0.01$). The percentage (73.4%) of psychiatrists who believed that patients knew about their treatment showed poor consistency with patients’ own reporting ($\kappa=0.193$, $p<0.05$). Psychiatrists were more likely to think that the patients had been involved in the treatment choice, and this was inconsistent with patients’ own reporting ($\chi^2=25.672$, $p<0.01$; $\kappa=0.077$, $p=0.304$) (Table 4).

Attitudes toward patients’ consent rights

Most psychiatrists (88.1%) and patients (76.1%) thought that the patient should be informed, unlike family members (26.6%). A high percentage (95.4% and 79.8%, respectively) of family members and patients believed that the patient could not refuse the treatment offered.

Patients’ capacity for informed consent and logistic regression analyses

Of the patients with schizophrenia, 30.3% were considered to be “impaired” in terms of their capacity to give informed consent to treatment. Compared with the “impaired” group, members of the “unimpaired” group had greater knowledge of their diagnosis (68.1% vs 45.9%, $\chi^2=5.002$, $p=0.038$) and treatment plan (77.8% vs 45.9%, $\chi^2=11.196$, $p<0.01$). There was no significant difference with respect to participation in treatment options between the subgroups (Table 5).

After controlling for educational level, social function during the past year, residence, and CGI-S scores, patients’ capacity for informed consent to treatment was independently associated with their knowledge of their illness diagnosis

Table 2 Basic demographic characteristics of patients (n=109)

Variables	n (%)	X ± SD	Diagnosis		Treatment	
			Statistic	p-value	Statistic	p-value
Sex			$\chi^2=0.560$	0.557	$\chi^2=1.042$	0.318
Male	53 (48.6)					
Female	56 (51.4)					
Age		42.46±1.29	F=0.919	0.340	F=3.623	0.06
Education (years)		12.67±0.2	F=0.172	0.679	F=0.345	0.558
Education (level)			$\chi^2=0.624$	0.732	$\chi^2=9.142$	0.01*
Middle school	28 (25.7)					
High school	43 (39.5)					
(Above) college	38 (34.8)					
Marital status			$\chi^2=3.006$	0.391	$\chi^2=1.714$	0.634
Single	61 (56.0)					
Married/cohabiting	23 (21.1)					
Divorced/separated	22 (20.1)					
Widowed	3 (2.8)					
Employment			$\chi^2=0.02$	1.000	$\chi^2=0.275$	0.671
Employed	37 (33.9)					
Retired	26 (23.9)					
Unemployed	46 (42.2)					
Premorbid character			$\chi^2=0.40$	0.816	$\chi^2=2.092$	0.351
Introverted	82 (75.2)					
Outgoing	13 (11.9)					
Neutral	14 (12.8)					
Income			$\chi^2=1.23$	0.304	$\chi^2=1.271$	0.282
High	18 (16.5)					
Middle	62 (56.9)					
Low	29 (26.6)					
Residence			$\chi^2=5.49$	0.026*	$\chi^2=4.405$	0.043*
City	88 (80.7)					
Country	21 (19.3)					
Social function (past year)			$\chi^2=0.88$	0.829	$\chi^2=9.811$	0.02*
Normal	2 (1.8)					
Mild disorder	25 (22.9)					
Moderate disorder	40 (36.7)					
Marked disorder	42 (38.5)					
Admission type			$\chi^2=4.1$	0.079	$\chi^2=0.76$	0.661
Voluntary	6 (5.5)					
Involuntary	103 (94.5)					
CGI-S		3.77±0.99	F=4.72	0.032*	F=4.537	0.035*

Note: * $p < 0.05$.

Abbreviations: SD, standard deviation; CGI-S, Clinical Global Impressions-Severity scale.

(odds ratio [OR] =3.230, $p < 0.05$) and their knowledge of treatment (OR =4.962, $p < 0.01$). Social functioning during the past year (OR =3.454, $p < 0.01$) and CGI-S (OR =0.305, $p < 0.01$) were independently associated with participation in treatment options (Table 6).

Discussion

This current study highlights the low rate of knowledge of illness diagnosis (60.6%) and treatment (67.0%) among patients with schizophrenia, and particularly their lower participation rate (25.7%) in their own treatment options.

At the same time, patients' family members knew more about their diagnosis and treatment. Furthermore, results suggest that the family of the patient is more involved in decision-making processes surrounding the treatment plan than the patients themselves are. Even though the family appeared, overall, to take on a more active role in the treatment plan decision-making processes, in 38.5% of cases reported here, family members said that they had never been involved in this process. In contrast, a study of nonpsychiatric hospitalized patients in Chengdu found that only 10.1% of patients did not participate in treatment options.¹⁸ So, it would appear that the

Table 3 Knowledge of illness and participation in treatment (patient vs family)

Variables	Patient (n=109)	Family (n=109)	χ^2	p-value
Diagnosis			27.147	<0.001*
Yes	60.6%	90.8%		
No	39.4%	9.2%		
Treatment			7.976	0.005*
Yes	67.0%	83.5%		
No	33.0%	16.5%		
Participation in treatment plan			28.376	<0.001*
Yes	25.7%	61.5%		
No	74.3%	38.5%		

Note: * $p < 0.01$.

informed consent rate and level of participation in treatment by schizophrenic patients was lower than that found in other clinical departments. In a review of the communication of a mental health diagnosis, it was suggested that a diagnosis of schizophrenia was disclosed at a lower rate (7%–59%) when compared with other mental health diagnoses (59%–96%) across a range of studies.¹⁹ Clafferty²⁰ reported that 41% of psychiatrists did not disclose a diagnosis of schizophrenia to patients in a first episode. Over 70% of Japanese psychiatrists have been reported not to inform patients about a diagnosis of schizophrenia.²¹ The consistency of the data from Western and Eastern countries might, to some extent, reflect the stigma existing around schizophrenia globally,^{22,23} particularly in Chinese culture. The underestimation of a patients' capacity to give informed consent may be another reason to explain this low rate of diagnostic sharing. In the current study, 40.4% of patients believed that they could make clear decisions more than half the time during their illness, although only 13.8% of families and 11.0% of psychiatrists thought so. The patients who were evaluated as having an impaired capacity to give their consent to treatment were demonstrated

Table 4 Knowledge of illness and participation in treatment (patient vs psychiatrist)

Variables	Patient (n=109)	Psychiatrist (n=109)	χ^2	p-value	κ	p-value
Diagnosis			1.626	0.257	0.462	<0.000*
Yes	60.6%	68.8%				
No	39.4%	31.2%				
Treatment			1.074	0.374	0.193	0.042*
Yes	67.0%	73.4%				
No	33.0%	26.6%				
Participate in treatment			25.67	0.000**	0.077	0.304
Yes	25.7%	59.6%				
No	74.3%	40.4%				

Note: * $p < 0.05$, ** $p < 0.01$.

Table 5 Patients' knowledge of their illness in subgroups (informed consent capacity impaired/unimpaired; n=109)

Variables	Impaired	Unimpaired	χ^2	p-value
Diagnosis			11.591	0.001*
Yes	36.4%	71.1%		
No	63.6%	28.9%		
Treatment plan			9.907	0.003*
Yes	45.5%	76.3%		
No	54.5%	23.7%		
Participation in treatment			0.052	1.000
Yes	24.2%	26.3%		
No	75.8%	73.7%		

Note: * $p < 0.01$.

to have less knowledge of their illness diagnosis and of their treatment.

Interestingly, with logistic regression analysis, we were able to determine that the patients' capacity to give informed consent to having treatment was independently associated with the knowledge of illness diagnosis and treatment. This confirmed our hypothesis that there would be a correlation between the capacity to give informed consent and the knowledge of illness diagnosis and treatment. However, in the current study, the patients' capacity to give their consent to treatment was not found to be independently associated with their participation in treatment options. This could be interpreted to mean that patients would not be invited to participate in their treatment option decisions proportionally to the severity of their illness, which could to some degree weaken patients' rights.

The findings reported here also indicate that stakeholders held different attitudes toward patients' rights to give consent. Family members had a low rate of support (26.6%), and psychiatrists had a high rate of support (88.1%). Most of the patients (76.1%) and psychiatrists (88.1%) thought that patients should be informed; however, the majority of family members (73.4%) claimed that patients did not need to know about their illness and that it should be managed completely by doctors. This inappropriate attitude might be a reason underlying the patients' lack of knowledge about their illness and treatment. Here, another interesting finding was the inconsistency between the supportive attitude of the psychiatrists toward the patients' rights to consent and the patients' lack of knowledge about their own illness and treatment. Nearly 90% of the psychiatrists supported the patients being informed, while only 60.6% of patients knew about their diagnosis (with the most common answer to, "why did you know little about your illness" being "I have not been told"). This phenomenon demonstrates that, to some degree, training enhances awareness, but did not

Table 6 The relationship between independent variables and patients' capacity for informed consent to treatment (n=109)

Variables	Knowledge of illness diagnosis	p-value	Knowledge of treatment plan	p-value	Participation in treatment options	p-value
	OR (95% CI)		OR (95% CI)		OR (95% CI)	
Education level	0.956 (0.574, 1.591)	0.862	1.014 (0.592, 1.738)	0.959	1.175 (0.642, 2.151)	0.601
Residence	0.374 (0.121, 1.156)	0.088	0.477 (0.145, 1.573)	0.224	1.147 (0.295, 4.464)	0.843
Social function (past year)	1.157 (0.650, 2.258)	0.620	0.508 (0.261, 0.987)	0.046*	3.454 (1.522, 7.837)	0.003**
CGI-S scores	0.730 (0.443, 1.202)	0.216	0.858 (0.507, 1.452)	0.568	0.305 (0.148, 0.631)	0.001**
Patients' capacity for informed consent to treatment	3.230 (1.250, 8.343)	0.015*	4.962 (1.759, 14.002)	0.002**	0.813 (0.259, 2.551)	0.723

Note: * $p < 0.05$, ** $p < 0.01$.

Abbreviations: OR, odds ratio; CI, confidence interval; CGI-S, Clinical Global Impressions-Severity scale.

lead directly to behavioral changes. Another possible reason that should be considered here is that many psychiatrists believed that schizophrenic patients did not have the capacity to understand the real meaning of their diagnosis if it was given to them.⁴ This result might also suggest that the informed consent process in mental health practice needs to be further implemented in the code of conduct and that psychiatrists should receive training in terms of appropriate and efficacious communication skills with patients.

Additionally, the results of our study described a low level of treatment refusal among patients (33.9%) and the family (29.4%). Most of the family members (70.6%) and patients (66.1%) thought that patients could not refuse the doctors' treatment. Out of the psychiatrists, 33.0% thought that the patients could refuse treatments themselves, while 57.8% of psychiatrists thought that the patients could refuse treatment after agreeing to do so with their family. The attitude toward treatment refusal might reflect the "patriarchal model" in psychiatric clinical practice, which might, to some degree, impair a patient's rights. Cultural beliefs and practices also exercised a very strong influence. In China, social integration was more important than autonomy. The treatment decision was generally at the family level.²⁴ Furthermore, the patient-doctor relationship in contemporary China is quite tenuous. Doctors might expect the whole family to be in agreement, especially with psychiatric patients needing long-term economic and spiritual support from their family members.

Limitations

The results of this study have several limitations. First, all the participants were inpatients from Shanghai with a relatively high level of education; such patients might have more knowledge of their illness than patients from other areas in China. Second, the sample size was small and so the study might not be representative of all patients with schizophrenia in China. Third, the data on clinical symptoms were not

analyzed thoroughly. Factors such as the patients' cognitive function and psychiatric symptoms might have affected the patients' knowledge of their diagnosis and treatment. Fourth, the knowledge of diagnosis and treatment among inpatients with schizophrenia was self-reported and may not be accurate. Meanwhile, we have not provided various options to the items when assessing knowledge because of the limitations of our questionnaire design. Fifth, the exact reasons for the cultural nuances and behaviors in our findings are still unclear. Therefore, further qualitative studies need to be performed to better understand our findings.

Conclusion

The current study, with some limitations, has highlighted the low level of knowledge surrounding illness diagnosis and treatment reported by inpatients with schizophrenia. This has been matched by complementary attitudes among the patients attending psychiatrists and their family members, and low rates of patient participation in treatment options. An association between patients' capacities to give informed consent and their knowledge of their illness has been demonstrated in the present study. The results suggest that the informed consent process for schizophrenic patients should be strengthened in clinical practice in order to protect their interests and rights.

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Disclosure

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